Integrating palliative care in Mulago Hospital and Makerere University

Health systems strengthening and values based change

Palliative care had started in Uganda with the founding of hospice Africa Uganda in 1993. This pioneering model was joined by Mildmay international a few years later which had a greater focus on HIV/AIDS. From the first the Ministry of Health was supportive and active including changing the legal statute to allow nurses and clinical officers who have appropriate training to prescribe oral morphine. This was the first time in any country that this had been approved. Initiatives such as clinical care with a community focus, education and training including undergraduate medical curriculum integration and postgraduate. Diplomas and now degrees have been developed by Hospice Africa Uganda with other stakeholders who include Makerere University, the oldest and most prestigious University in East Africa. Patients were visited in hospital including the government hospitals but there was still no real ownership or leadership from within the government health system and many examples of poor palliative care attitude, ignorance and myths regarding the use of oral morphine and poor patients care. A multi-stakeholder steering group facilitated the starting of a palliative care service at Mulago Hospital, the only national referral hospital in Uganda. This was 4 MOH nurse initially (2006) and then became a more comprehensive, multidisciplinary team in collaboration with the Department of Medicine in Makerere University. Thus was formed the Makerere and Mulago Palliative Care (MPCU) unit in 2008 with leadership from a UK trained palliative care physician (Dr Mhoira Leng) with experience of hospital integration models and a Uganda doctor committed to training in specialist palliative care (Dr Liz Namukwaya)

What were the main challenges?

- How to integrate palliative care within a government and academic institution?
- How to foster and support a culture of evidence based practice?
- How to influence the values of a health system to recognise, own and deliver palliative care?
- How to improve access to quality palliative care?

What were the key barriers?

- Credibility
  - leadership, speciality recognition, research
- Ownership
  - clinical services, modelling, empowerment and training
- Scarce resources
  - human, financial, environment
- Attitudes and values
  - pain management, emphasis on curative approach, opiophobia

How did we achieve change?

MPCU agreed a 5 year strategic planning process with clear goal, vision and objectives. Key to the implementation was strong international collaborations in particular with the University of Edinburgh, Global Health Academy and Primary Palliative care Research group. All outcome measure of the strategic plan were incorporated into a comprehensive research agenda that showed the important link between need, appropriate models of care, strategic planning, and development of evidence based practise though practice based research. This process is outlined in the attached paper submitted as a chapter in the
conference proceedings of IAPCON 2014. Crucial to this model was integration and this was further underlined by 2 pieces of research work showing levels of need. A point prevalence study of medical and surgical wards in Mulago hospital revealing 45% of patients had life limiting illness and met palliative care needs and a hospital woe census revealing 37%. With a bed capacity frequently running over the official count of 1900 then the needs for patients and then also the family members can seem overwhelming.

Goal;
To scale-up and implement a sustainable, Ugandan-led model Palliative Care Unit in collaboration with our partners, which delivers and demonstrates a quality evidence-based service at the Mulago hospital site and carries out research, training and capacity building.

Vision;
Access to evidence-based, quality palliative care for all in need in Uganda, sub-Saharan Africa and beyond.

Strategic objectives;
1. **Clinical Service Provision.** To provide and scale-up an integrated clinical service to patients and families on the Mulago hospital site.
2. **Education and Training.** To provide education, training and capacity building for healthcare workers at undergraduate and postgraduate level.
3. **Advocacy.** To enhance and promote academic and clinical credibility for Palliative Care
4. **Research.** To expand the evidence-base for palliative care by encouraging a research culture, and supporting and initiating research into palliative care in Africa.
5. **Sustainability.** To develop a well-resourced Palliative Care Unit, with the capacity and infrastructure capable of supporting a sustainable Ugandan-led team.

*What has been achieved this far?*

**Clinical service provision;** 600 patients are seen directly by the multidisciplinary team (nurse and doctors all trained to specialist level) and categorised using a novel tool. Level 1 are needs which could be met at generalist level if curriculum integration and in service development is available. Level 2 needs should be provided by health care and social workers that have some addition training and supervision. This we provide via our unique link nurse model. Level 3 and 4 both have complex needs and need interventions from health and social care workers with specialist skills. When the specialist referrals are made (usually level 3 and 4) the MPCU team assess using standards tools including the APCA. African POS and offer consultation, shared care and occasionally sole care. We do not have dedicated beds or OP or home care as we freer to the community based programmes such as Hospice Africa Uganda. The MPCU also support and mentor the link nurses who in turn see a further 2000 patients. A key part of the MPCU tram has been the developed net of a volunteer programme. 15 volunteers have been trained and are supervised by our pastoral and social care coordinator and in turn provide support Manila in the form of practical, pastoral and social. This can include helping get medications, wheeling beds down to access investigations for those unable to walk, making contact via phone or even internet with family and community beds or listening, befriending or praying with patients and family members. In turn the volunteers learn life skills and are able to offer a humanitarian contribution so essential in community empowerment. Patients referred and assessed still mainly have cancer but due to our unique position as a unit within the department of
medicine and receiving referral from all parts of the national hospital site we also see many patients with HIV/AIDS and advanced organ failure such as renal or hepatic disease.

‘you gave me hope, you gave me pain control, you gave me love....thank you and please pray for me...make sure everyone in Uganda has this care.’ Rose; patient

Training: this is at the heart of all we do as we seek to instil and inspire the knowledge, attitude and values needed to deliver quality, evidenced based palliative care. We share the undergraduate medical teaching with Hospice Africa Uganda and also support undergraduate nurses training. We participate and partner in the delivery of the diploma and degree in palliative care offered by Makerere University through Hospice Africa Uganda and the Institute for Hospice and Palliative Care in Africa. We have also developed one of the first integrated curricula for postgraduate doctors training in specialist is where they will need core competencies in palliative care to support the many patients and families with chronic life limiting diseases. Thus far we teach all Internal medicine MMed students, all family medicine MMed students and some put to ENT, general surgery and gynaecology oncology as well. This has made a huge impact. Quoting a current student: crucial to see behavioural change and challenging values is clinical modelling. We ensure all the students we train have both classroom time but also opportunities to observe this in practice and to test out their learning with mentorship and supervision. Students and colleague’s come from across Africa, from the UK and the rest of Europe, from India, from Australia and New Zealand and from the USA to observe, participate and share rich learning.

‘This has been a wonderful experience. It has taught me to be a better doctor in the future. 5th year med student, Makerere

‘The palliative care training has made a huge impact; I now see the patient as a person and not a disease, I don’t avoid difficult conversations, I don’t order unnecessary investigations, I see them as part of a family, I do holistic care. It was not like that before.’ MMed doctor in training, Makerere.

Research: practise based research underpins the work of the unit. The research agenda has proved invaluable and is combined with many levels of reset ah capacity training and support. This has allowed first time researchers and students to produce their first research work but also Masters, PhD and postdoctoral studies. Research is divided into 3 strands. 1. Patients, family and carer issues 2. Staff and health care provider issues 3. Health systems and processes issues. We have been able to publish over 70 abstracts at national, regional and international forums in the past 4 years. This has included a full evaluation of the link mum dole of integration, impact of postgraduate training, needs assessment in Mulago hospital but also regional hospitals such as Gulu and Kabale elsewhere in Uganda, experience of breaking bad news for clinicians, information needs of patients, development of a novel volunteering programme and the experience of patients with hepatocellular carcinoma.

‘The course was good with all the contents worth utilizing, lets work together to improve research in Africa’
‘Thanks for the entire faculty of this training. You have been an eye opener to my research career’
Participants on the first Advanced Research School in Africa

Advocacy: As one of the first combined clinical and academic units in Africa we have an important role in advocacy. This is particularly important as we can speak with evidenced based authority about integrating palliative care in government systems in a culturally appropriate way yet within resource constrained health systems. We can also address the issues of values change. With the current global agenda encouraging just such models of care we have an important voice to be heard. Nationally we are part of the
country lead team for palliative care led by the MOH and have recently participated in the development of a national policy for palliative care. Our MPCU protocols have been adopted by the MOH and also adapted and adopted in Zambia, Rwanda and parts of Kenya. We host along MOH and senior colleagues from many countries who wish to understand this model and how it might be adapted on their own setting from many other countries in Africa. members of our team are active in the global palliative care world including board members of the International Hospice and Palliative Care Association (IHPCA) and the International Children's' Palliative Care Network (ICPCN) and the Indian Association for Palliative Care (IAPC). Our strong collaboration with the Global Health Academy has also been a hugely important part of our advocacy work and shows the gain from North South as well as South South linkages.

'I really highly appreciate the enthusiasm and quality of hospitality you've shown us. This reflects the heart of humanity in health providers. Learning from you empowers us to transform the whole Rwandan society in having a therapeutic culture. We don't doubt that other countries can learn from us as we have learned from you. Yours in solidarity....' Colleagues from Rwanda on placement

**Sustainability:** this remains the most challenging of our strategic objectives. We have visibility, credibility, increased capacity and successful integration but few positions on the specialist team funded within Makerere University or the Ministry of Health compliment and are therefore reliant on grants for ongoing function. Work to plan country wide implementation linked to public service deployment alongside continuing advocacy with hospital and university management seeks to address this challenge. However sustainable funding for palliative care remains a challenge in many parts of the world.

See attached
MPCU summary ppt

Strategic planning and Health system strengthening paper

Cairdeas website [www.cairdeas.org.uk](http://www.cairdeas.org.uk) and Dr Mhoira Leng blog [www.mhoiraleng.blogspot.com](http://www.mhoiraleng.blogspot.com)

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